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ABSTRACT

The paper describes the rationale behind the Charlotte Circle Project, a program which is developing and implementing a social reciprocity curriculum for very young severely handicapped children and their parents. The normalization principle suggests that interventions be age appropriate and functional. For children younger than 3 years an age appropriate and functional intervention program would emphasize social reciprocity recognizing the fact that parent-child interactions are often interrupted and distorted because of such child characteristics as nonresponsiveness, inability to "take in," to feel comfort, atypical motor responses, and atypical daily living needs. The curriculum stresses the need of parents to feel competent about handling the young child, to feel effective in meeting the child's needs, to observe positive changes in return for their caregiving; and the need of the child to sustain the caregiver's attention, to communicate needs, and to develop satisfying relationships. The project's implementation strategies include an early intervention model that is both home-based and center-based and the establishment of individualized social reciprocity goals for both parent and child. (DB)

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Working Paper #1
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ABSTRACT

Questions have been raised about the most appropriate and helpful interventions for very young children with severe/profound handicaps. The normalization principle provides important guidance by suggesting that interventions be age-appropriate and functional. For children younger than three years, an age-appropriate and functional intervention program would emphasize social reciprocity, acknowledging and focusing on the reciprocal and circular nature of parent-child interactions. For severely handicapped infants and young children, the reciprocal nature of parent-child interactions is interrupted and distorted because of certain child characteristics: e.g., nonresponsiveness, inability to "take in," to feel comfort, atypical motor responses, and atypical daily living needs. Social reciprocity interventions address the needs of severely handicapped infants and their families: parents need to feel competent about handling their young children, to feel effective in meeting their child's needs, to observe positive changes in return for their caregiving; the child needs to sustain the caregiver's attention, to communicate needs, and to develop satisfying relationships. The Charlotte Circle Project is developing and implementing a social reciprocity curriculum in a program serving very young children with severe/profound handicaps.

Social Reciprocity: Early Intervention Emphasis for Young Children with Severe/Profound Handicaps

Early intervention has been described as a "critical investment in the future of mentally retarded children" (Rogers-Warren & Poulson, 1984) and yet the younger the child and the more severe the handicap, the less likely is the probability of accessible and appropriate intervention. Hayden (1979) has noted that the service gaps are most dramatic for infants and children under 3 and that the quality of services varies most widely for this group. The service gap for this young severely handicapped group can be attributed to many factors including the low incidence of this type of developmental disability, questions about the usefulness of intervention for severely impaired children, and lack of readily accessible effective intervention strategies.

The low incidence of severe and profound handicaps makes the development of effective interventions difficult. While estimates of the prevalence of mental retardation in the population as a whole range from 2% to 3%, persons with severe and profound handicaps comprise only a fraction of that group. In a review of prevalence studies, Abramowicz & Richardson (1975) suggest that the prevalence of profound mental retardation (IQ below 20 or 30) in the general population is .66 per 1000. Roberts (1981) suggests that programs for severely and multiply handicapped children under 3 years of age are quite rare; most preschool programs for the handicapped

operate on low budgets and provide services for mildly and moderately handicapped children or children at risk for handicaps rather than this severely impaired group. Even in communities where early intervention services exist, severely handicapped children may be unserved or underserved. In many communities an early intervention program may enroll only one or two severely handicapped children; the program may then be geared toward the needs of those children with less severe developmental disabilities. (Calhoun & Rose, 1986).

There are those who question the usefulness of intervention for severely and profoundly handicapped children. Recently, several authors have questioned the educability of severely handicapped children and society's responsibility to them (Kauffman & Krouse, 1981; Burton & Hirschoren, 1979). Some professionals note that there are no studies showing that profoundly handicapped children can be made into functioning, semi-independent persons who can survive in the community (Bailey, 1981; Ellis, 1979) and the training efforts with profoundly handicapped individuals have been described as "abusive" (Noonan, Brown, Mulligan & Rettig, 1982).

Proponents of early intervention respond to the "educability" issue with studies demonstrating progress in all domains of development (Stainback & Stainback, 1983) and by citing Constitutional guarantees of "equal protection" and "due process". There remain, however, questions about the most appropriate and effective intervention strategies that will

enhance the quality of life and help very young, severely handicapped children develop to the extent possible.

Most existing programs that attempt to meet the needs of very young, severely handicapped children typically have a strong skills orientation, that is, they attempt to stimulate the child toward developmental gains in a normal sequence in language, social, cognitive and motor domains. Some professionals have raised a concern about the focus of special education on narrowing the gap between the perceived handicap and the perceived notion of normal behavior. Langley (1980) points out that while skill acquisition may be exciting in itself, the gap between severe mental retardation and normal development remains wide. Parents may remain more aware of this gap than professional caregivers and disappointment about program effectiveness may be severe. It would seem that a skill development curriculum is a necessary but not sufficient early intervention strategy.

When we ask the question of what are the most appropriate and helpful interventions for young children with severe/profound handicaps, the principle of normalization provides important guidance. Nirje (1979) describes normalization as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181). In developing intervention programs for adolescents and adults with severe handicaps, arguments based on the normalization principle have urged an intervention emphasis on chronological age-appropriate and functional skills. Brown,

Bransta, Hamre-Nietupske, Pumpian, Certo and Gruenewald (1979) have stated that if one goal of education is to minimize the stigmatizing discrepancies between the handicapped and others, it is our obligation to teach handicapped individuals the major functions of their chronological age using materials and tasks which do not highlight deficiencies. Additionally, Brown and his colleagues (1979) argue for the teaching of functional skills, a variety of skills that are frequently demanded in natural domestic and community environments. Age-appropriate and functional activities are seen to have at least two important outcomes for individuals with severe/profound handicaps: first, the self-esteem of mentally retarded individual is enhanced by participation in normalized activities and by increased competence and, second, community rejection and ostracism may be reduced when stigmatizing differences are minimized (Rusch, Chadsey-Rusch, White & Gifford, 1985).

Age-appropriate and functional interventions for very young children with severe/profound handicaps must take into account typical activities of children under 3 years of age and typical demands that occur in the child's natural domestic and community environments. For children under the age of 3, interactions with parents and other caregivers are central to the child's development (Barrera & Rosenbaum, 1986). The age-appropriate "work" for very young children is to establish a satisfying relationship with caregivers. This relationship will lead to increased stimulation, attention and support. The behavior of the child affects the behavior of

the parent which in turn affects the behavior of the child. Intervention which acknowledges and focuses on the reciprocal and circular nature of parent-child interactions can be called "social reciprocity interventions."

Social Reciprocity

A crucial change has taken place in past decades in child development literature: there has been a shift from a unidirectional model that recognizes the child's contribution to his/her own care. The concept of a reciprocal bi-directional influence between the child and the environment was introduced formally by Bell (1974) in his reexamination of the literature on early socialization. Bell (1974) defined the "parent-child system" as "... a reciprocal relation involving two or more individuals who differ greatly in maturity although not in competence, in terms of ability to effect each other." Not only is the infant or child influenced by its social world but the child itself influences the world in turn. Behavior occurs in interaction. The infant's behavior can be in response to or can initiate a parental behavior. For example, Lewis and Lee-Painter (1974) found that 44% of infant behavior occurs in interaction, with smiling always a response to another's behavior and babbling frequently a response to another's behavior.

Bonding and attachment are stages in the on-going interactional process between infants and their primary caregivers (Bromwich, 1978). The process is set into motion as the infant gives signals or behavioral cues

to parents who read and respond to these cues. The parent, in turn, gives signals that the infant gradually learns to read. This reciprocal reading and responding to each others' cues forms the core of a complex interactional system that influences the child's development (Brazelton, T. B., Koslowski, B. & Main, M., 1974).

Social Reciprocity Needs of Severely Handicapped Infants and Their Families

A "socially competent" infant elicits positive responses from the parent. On the other hand, the child who is difficult to read, unpredictable or non-responsive brings about parental feelings of inadequacy that can contribute to parental unresponsiveness and behaviors that do not make a positive contribution to the child's development (Goldberg, 1977). In recent years, interactional models of early intervention have been created to support the development of parents and their environmentally or biologically at-risk infants (Bromwich, 1978; Barrera & Rosenbaum, 1986). These programs focus intervention on the parent-infant interaction in order to increase the efficacy of those interactions.

Social reciprocity interventions are especially crucial for those children who are clearly identified as severely or profoundly handicapped. The reciprocal nature of parent-child interactions is interrupted and distorted because of certain characteristics of severely/profoundly handicapped children. These characteristics include non-responsiveness — the child's inability to "take in," to thrive and to feel comfort; atypical

motor responses; and atypical daily living needs. Ramey, Beckman Bell, and Gowen (1980) identify four different ways that a handicapping condition can alter parent-child interactions:

1) It can influence the rewards parents derive from parenting.

A baby develops increasingly complex behaviors that make caring for the baby, more rather than less, reinforcing. The care of infants with delayed and atypical development may not be as rewarding. As an example, Campbell & Wilson (1976) identified the two most significant factors in the development of a meaningful communication system as: (a) the establishment of reciprocal gaze patterns between infant and primary caregivers; and (b) the infant's subsequent smiling behavior. In normal babies, these responses occur at about one month of age. The activity of eye contact with mother causes the baby to smile which in turn motivates the mother to play more often with her baby. For severely and profoundly handicapped children, non-responsiveness may interfere with these prosocial behaviors for months and years.

2) The child's handicap can influence the caregiver by making routine caregiving activities, such as handling and feeding, more difficult.

A mother's efforts to cuddle her severely disabled infant with motor involvement may be met with body extension and retraction instead of the expected molding to her body (Langley, 1980). Such behavior may cause a parent to feel rejected by the infant or it may seem that the child is expressing physical discomfort from the way in which she is being held. A

parent may feel ineffective as a caregiver which further complicates and prohibits positive interaction with the child (Buch, Collins, & Geller, 1978). Beckman-Bell (1980) found that the number of additional or unusual caregiver demands presented by an infant was directly related to the amount of stress reported by mothers.

3) The separations that sometimes result from the need to hospitalize handicapped children can results in disruptions of the parent-child relationship.

4) An area of indirect influence refers to what have been labeled as contextual variables. Such factors as the reactions of friends and strangers to the handicapped infant; financial pressures; and marital stress can act to influence the interaction between parent and infant.

A review of observational studies of the interactions between parents and handicapped babies does reveal atypical parent-child interactions. Several investigations focusing on the interactions of the mother-mentally retarded child dyad have suggested that mothers of young retarded children initiate fewer interactions and are less likely to respond positively to their children than are mothers of non-retarded developmentally matched children (Crawley & Spiker, 1983; Cunningham, Reuler, Blackwell & Deck, 1981; Eheart, 1982; Levy-Shiff, 1986). In these same studies, mentally retarded children were found to be less responsive: they laughed, smiled, vocalized, spoke to and moved toward their parents less often than did non-mentally retarded children.

Clearly, the interaction between severely handicapped young children and their caregivers is frought with special challenges.

Implementing Social Reciprocity Interventions

The Charlotte Circle Project, a model demonstration program funded by Handicapped Children's Early Education Program (HCEEP), U. S. Department of Education, has established the goal of developing a social reciprocity curriculum for very young severely handicapped children and their families. The following implementation strategies have been developed:

1. An early intervention model that is both home-based and center-based has been established.

The center-based program is offered daily in a special education center. Transportation is provided. Parents can elect to enroll their children in a 3-day a week or 5-day a week program. This center-based component not only offers intensive educational and therapeutic intervention for young children but offers families some respite hours from the responsibility of caring for their child with special needs. Because parents don't have the entire responsibility, 24 hours a day, for meeting the developmental needs of the child, the hours for which parents are responsible may be filled with more energy and optimism.

A home-based component enlists parents in joint planning of the child's program. Bi-weekly home visits are used to share information, to identify areas of concern in managing daily routines, and to share

intervention strategies with other important people in the child's life such as babysitters, siblings and grandparents.

2. Social reciprocity goals are established for each child in the program, based on observational studies. Direct instruction is provided on a daily basis. In general terms, social reciprocity goals include the following:

a. Children will increase their social responsiveness to primary caregivers. Increased responsiveness includes sustained eye contact, smiling, more normalized responses to voice and touch.

b. Children will reduce the frequency and duration of behaviors parents identify as stressful, aversive and unpleasant. The behaviors include prolonged crying, vomiting, drooling, self-injury and self-stimulation.

c. Children will make progress in acquiring skills in the following domains: gross and fine motor, language, social, and cognitive, in a total stimulation curriculum.

3. Social reciprocity goals are established with parents as well and are addressed not only through the home-based component but through parent-child days at the center and group meetings. Social reciprocity interventions encourage parents to see things from the child's point-of-view, to know the abilities and limitations of the child, to be sensitive to needs and signals. These goals include the following:

a. Parents will participate with their children in mutually satisfying social interactions.

b. Parents will demonstrate and express increased competence in meeting the daily needs of their child, including health care, feeding, bathing, dressing, handling, comforting.

c. Parents will report and demonstrate an increasingly normalized family life.

In summary, a social reciprocity intervention program would seem to hold promise for both severely/profoundly handicapped young children and families. Parents need to feel competent about handling their children, to feel effective in meeting their child's needs, to feel love and affection and to observe positive change in return for their caregiving. Their child's atypical responses may inhibit the development of these parental feelings and consequently may alter parental behavior. The child also needs to be effective: to initiate contact with his/her caregiver, to sustain the caregiver's attention in a positive way, to communicate needs to the caregiver so that the needs can be met, to develop a satisfying relationship with important persons in his/her life. Social reciprocity interventions can provide an important focus for early intervention with young severely handicapped children and their families.

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